# Awareness can be best medicine

## Parents who lost son to celiac disease want to shed light on often-overlooked ailment

By CARY LEIDER VOGRIN
THE GAZETTE

Every time Brian Adair ate two of his favorite foods — strawberry Pop-Tarts or peanut butter on white bread — his body attacked itself.

With each swallow, the lining of his small intestine became more damaged.

Neither Brian, 13, nor his parents had an inkling that the food, instead of sustaining him, was hurting him.

He died April 4.

Tests revealed Brian had celiac disease, which might have caused his heart to stop and the rest of his organs to shut down.

Five months after Brian died, his parents, Mary and Duane Adair, finally can talk about it. They want others to know about a disease that only now is getting widespread attention in the United States.

"They say people don't die from that," said Mary Adair. "Well, evidently they do. That's what I want people to know."

Celiac sufferers cannot tolerate the protein gluten — found in everything from crackers and cookies to pastas and pizza crusts.

Such foods cause the immune system to assault the lining of the intestine and prevent nutrients from being absorbed.

Cases such as Brian's are rare, but the nation's top celiac experts say the disease is grossly underdiagnosed and much more common than previously thought.

A study released this year from the University of Maryland School of Medicine found as many as 1 in 133 people might have celiac disease.

Another study of children in metro Denver, to be published this month by the Journal of Pediatrics, says 1 in 100 children might show evidence of celiac by age 7.

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BRIAN ADAIR: Until early this year, the 13-year-old appeared mostly healthy.

**ON THE NET**

- **Celiac Sprue Association, Pikes Peak Chapter:** www.geocities.com/ppccsa/
- **The Celiac Sprue Association/United States of America:** www.csaceliacs.org
- **The Celiac Disease and Gluten-free Diet Support Page:** www.celiac.com

outside the breadbox 633-3434

I25 to exit 144 go west to 14th st exit go north stop sign(7-11) next block 2 buildings down.



1508 W. Colorado 15th & Colorado N-W corner Blue Victorian

# DISEASE: Celiac symptoms can vary

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The numbers are nowhere near previous estimates of 1 in 5,000 or 1 in 10,000 people.

Few people, however, have heard of the disease, for which the only treatment is a change in diet.

Compounding the problem is that many with the condition are silent sufferers who show few, if any, symptoms.

They can be people like Brian.

## TESTS NEVER FOUND ANYTHING

Until early this year, Brian appeared to be a healthy teen who rarely needed a doctor, his parents said.

His teeth were his only obvious problem. Enamel wouldn't form on them, and Brian made frequent visits to the dentist. The Adairs now realize his dental problems possibly were a sign of celiac.

A few times Brian lost weight, but tests never found anything wrong.

Although he was a picky eater, his parents didn't really worry about his strange diet.

"His health wasn't a real issue to us," his mom said.

"He was growing fine. He was happy, healthy. Mentally he was excelling."

Brian called himself a "fruitatarian" and wouldn't touch vegetables or meat. He didn't like french fries or chips. Although his dad, Duane, worked at Papa John's, he wouldn't eat pizza, either.

He was gearing up, though, to try other foods.

"He told us to buy some broccoli. He was going to try broccoli," his mom said. He picked it, she said, because green was one of his favorite colors.

His quirky ways extended throughout the kitchen.

Of all the knives in the utensil drawer, he would use only one particular knife. He even took it on vacation to his grandparents' homes in Texas and Durango.

"That knife went where he went," his mother said. "He was your average kid who wasn't so average."

A couple of years ago, a counselor suggested Brian was mildly autistic, although he never received a formal diagnosis.

Studies have shown no link between autism and celiac disease, but experts say it's possible celiac caused some of his autistic-like behavior.

Although some of Brian's oddities were perplexing — such as making sure Kool-Aid packets were in a certain order in the cupboard — others were astounding.

Brian, the third of four children, started reading as a toddler and was teaching himself Japanese last summer. For Christmas, he asked for books and tapes on the language.

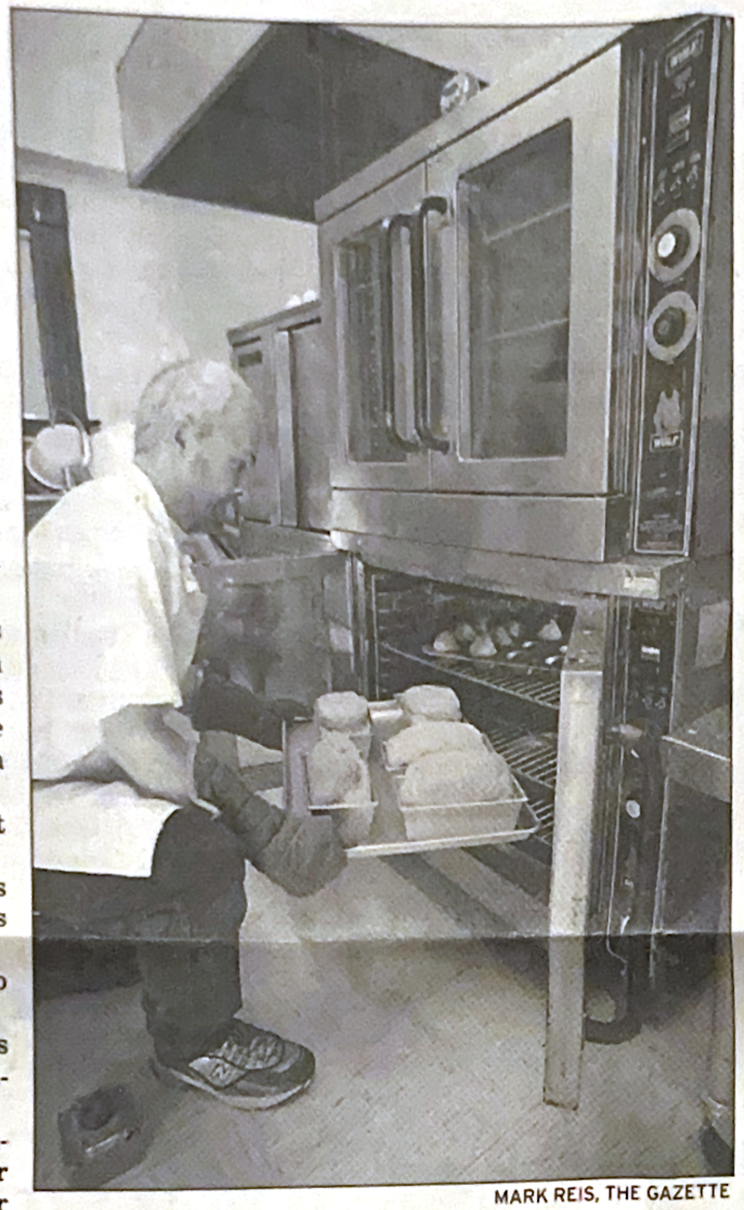
"He was gifted," said his mom. "The child was very gifted."

He enjoyed watching spelling bees and quiz shows such as "Jeopardy" and "Who Wants to Be a Millionaire."

In a binder of lined notebook paper, he drew characters he hoped to one day incorporate into video games of his own creation. He'd make up math problems to solve, just for the fun of it.

Brian was home-schooled and had little affinity for sports or socializing with other kids. He most enjoyed spending time with his 18-year-old brother, Chris, whom he considered his best friend.

Still, Brian welcomed people into the family's home in Vista Grande, near North Academy and Meadowland boulevards. Visitors could be guaranteed a hug and a conversation about anything from Brian, Duane Adair said.



MARK REIS, THE GAZETTE

**SAFE TO EAT:** Rick Hasty turns gluten-free loaves in an oven this month at Outside the Breadbox on West Colorado Avenue. Pam and Rick Hasty opened their bakery June 1. The couple's daughter, now in college, was diagnosed with celiac disease as a toddler. "We knew how hard it had been for us to find food that tasted good, and we believe there was a need out there," said Rick Hasty. He makes gluten-free bread each day, as well as rolls, buns, pizza crust, cookies and muffins.

## RAPID DECLINE

Brian began throwing up a little more than a month before he died.

"We figured it was the flu bug," said Mary Adair. The vomiting would stop, then start again.

After a week, he went to the doctor. Nothing appeared amiss; some sort of virus was presumed.

In three weeks, Brian lost 13 pounds.

March 26, he was admitted to Penrose Community Hospital.

Tests revealed gallstones, and he underwent surgery the next day. He seemed better immediately afterward, so much so that his mom took some of his belongings home.

Then the vomiting began again. Brian's condition worsened to the point he didn't recognize his family.

April 1, after going into cardiopulmonary arrest and undergoing resuscitation, he was transferred to Memorial Hospital's pediatric intensive care unit.

Dr. Christopher Johnson, who saw Brian at Memorial, knew the boy's chances for survival were not good.

"What we were dealing with was someone who had multiple organ failure after cardiopulmonary arrest," he said.

At his parents' request, Brian was placed on a "do not resuscitate" status.

A day after Brian went to Memorial, results came back from a biopsy done at Penrose.

"The findings were very consistent with celiac disease," according to Brian's medical records.

Earlier recognition of the condition might have prevented Brian's cardiopulmonary arrest, he said.

On Brian's medical records, "celiac crisis" is listed as the cause of death.

The Adairs don't blame anyone for Brian not being diagnosed.

"They were gold to us," Mary Adair said of the numerous doctors who tried to help.

"They still are."

Dr. Alessio Fasano, the principal investigator in the celiac study conducted by the University of Maryland, said that as recently as the mid-1990s, celiac disease was not widely known.

"It was considered extremely rare and didn't warrant much attention," said Fasano, whose study was highlighted on the "Today" show and made the front page of The Washington Post.

Part of the problem is that many doctors have been trained to recognize celiac only from classic symptoms: bloated bellies, weight loss and diarrhea.

Celiac often isn't suspected in adults because doctors have been taught to look for it only in children.

It's not uncommon for people to live with celiac for years — even more than a decade — before getting a diagnosis.

"For each person with symptoms, we find three or four without symptoms," Fasano said.

Fasano said if 1 in 133 people suffer gluten intolerance, celiac is the most frequent genetic disease in humans by far.

The numbers would mean a few thousand people in El Paso County have celiac.

## PAIN OF LETTING GO

Mary Adair has nightmares about her son's final days.

Someone suggested it might help if family members wrote down recollections of Brian.

Sticky notes in pink, blue and lime green decorate her refrigerator.

"Brian was weird, but in a semi-good way," one reads.

"The bigger the challenge for Brian, the better. He loved to be tested, just to see how good he wuz."

"Brian liked the smell of popcorn but never dared to eat it . . . go figure."

About a month after Brian's death, at a stoplight on North Academy Boulevard, Duane Adair got an unexpected but deeply touching reminder his son.

A driver motioned him to roll down his window and asked if he was Brian's dad.

In a quick conversation before the light changed, the man explained he was a tech at Penrose when Brian had been there.

Brian, he told Duane Adair, was a neat kid, a pleasure to be with.

The Adairs' other children have been tested for celiac. None tested positive.

Mary Adair said she only hopes Brian's story educates others.

"He always wanted to help people. Maybe this is his own way," she said.

"All we want to do is alert people that there is something in this world called celiac disease."

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## ABOUT CELIAC DISEASE

**Symptoms:** Classic symptoms include diarrhea, protruding belly and weight loss. Other possible symptoms: behavior changes, failure to thrive in children, tingling/numbness in legs, tooth discoloration/enamel loss, anemia, belly pain, itchy skin rashes, fatigue.

**Who might want to discuss testing with their doctors:** People with Type 1 Diabetes, irritable bowel syndrome, infertility problems or osteoporosis.

**How it's diagnosed:** Blood test is done first. If the test suggests evidence of celiac disease, a biopsy is performed. The biopsy is a routine, outpatient test.

**Treatment:** A gluten-free diet, which, for many, means a radical change in eating habits.

Dr. Joseph Murray, a celiac expert from the Mayo Clinic, said the median age of diagnosis is 45.

Sometimes the disease, which is hereditary, isn't detected for years. It can come become serious at any time in life, triggered by many factors such as a pregnancy, a gastrointestinal infection, stress or surgery. It affects females twice as often as males, said Murray, who agrees celiac disease is much more common than previously thought

Murray said there is a big push to educate doctors about the condition. "You actually have to be aware of the disease and suspect it," he said.

The National Institutes of Health is planning a conference about the disease next year.